How Exactly Does One Access NASA Space Life Sciences Data?

Mary Van Baalen
Manager, Lifetime Surveillance of Astronaut Health Program

2013 HRP Investigators' Workshop
Plenary Session

February 12,2013

Data Accessibility

- Until ~2010, the only astronaut data available to researchers was de-identified or grouped data archived within the Life Sciences Data Archive (LSDA)
- We are developing processes to enable release of individual data from both research and medical archives
- Survey questions you answered at registration are used to give us continuing insight into what data researchers need and how it is used, so we can continue to evolve to better meet the needs of the research and operational communities

Prospective Research

- HRP has well-established data sharing processes for purely prospective data
  - Flight research facilitated by ISS Medical Project (ISSMP):
    - Integrates informed consent briefings with crew
    - Develops Increment-specific Data Sharing Plans
      - Exchange of research data among PIs with attention to protecting rights of first publication
      - Documents medical data to be released from LSAH for research studies
  - Flight Analog research facilitated by Flight Analogs Project (FAP)
    - Analogs: such as Bed Rest Study at UTMB, and NEEMO
    - Similar, campaign-specific Data Sharing Plans for the exchange of research data
    - Bed rest data available includes Standard Measures data

Retrospective Research
via Life Sciences Data Repositories

LSDA
Life Sciences Data Archive

Research Data

- Active archive of HRP research
- Historical flight data 1961-Shuttle
- **Ground-based and flight analog data**
- Human, animal and plant data
- **Animal biospecimens available for research**

LSAH
Lifetime Surveillance of Astronaut Health

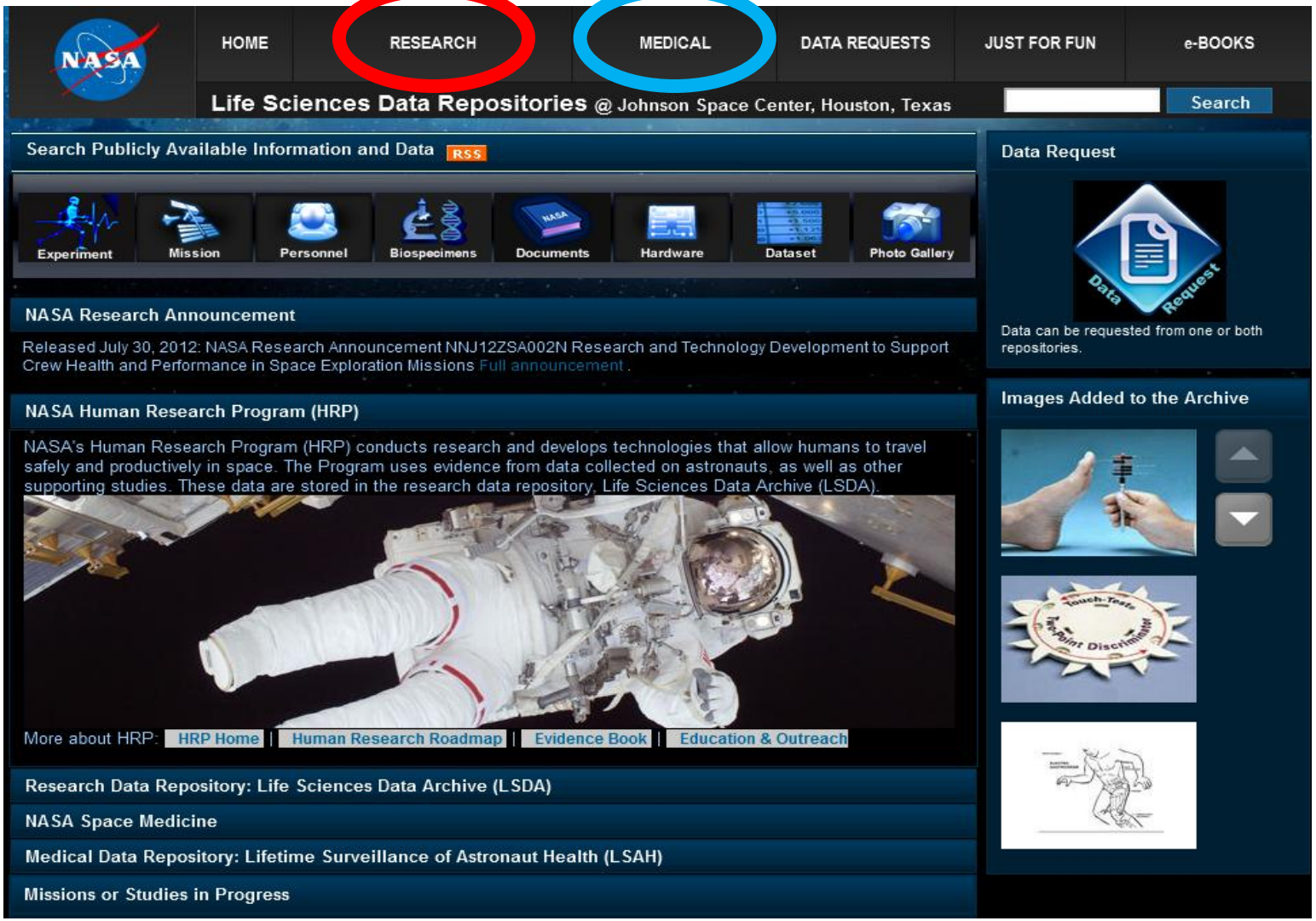
Medical Data

- Data for all astronauts selected to the corps beginning in 1959, including retirees who return for annual exams
- Includes ground & flight medical exam & mission health data (e.g., MRID/MEDB, vehicle, environment data)

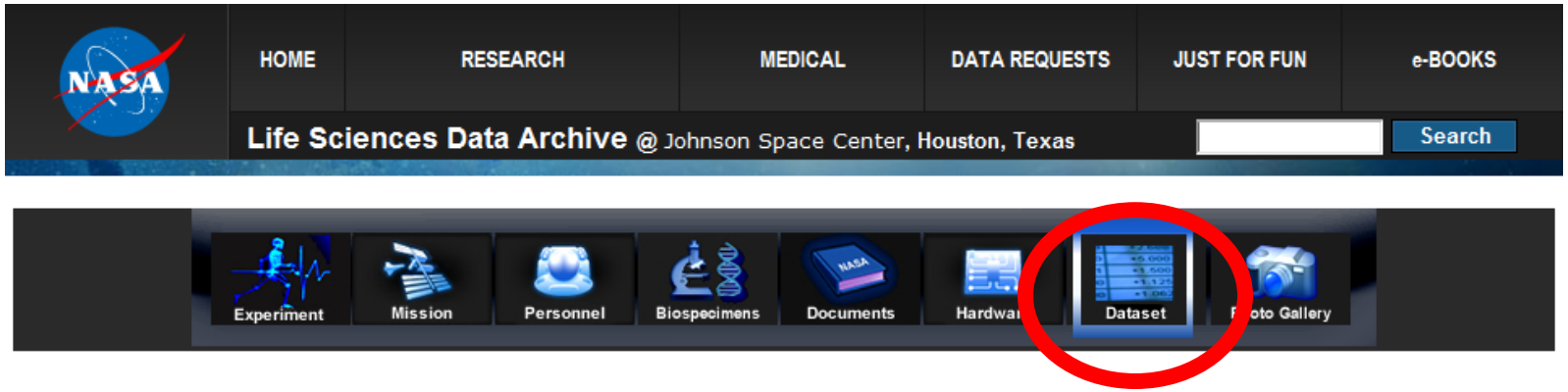
Future Plans

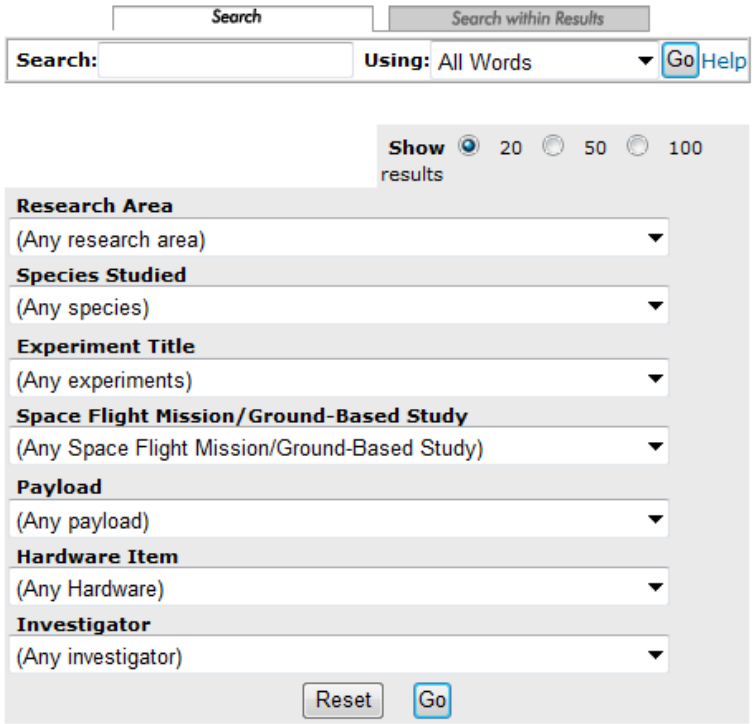
- **Human Performance Database**

Information on Public Website lsda.jsc.nasa.gov



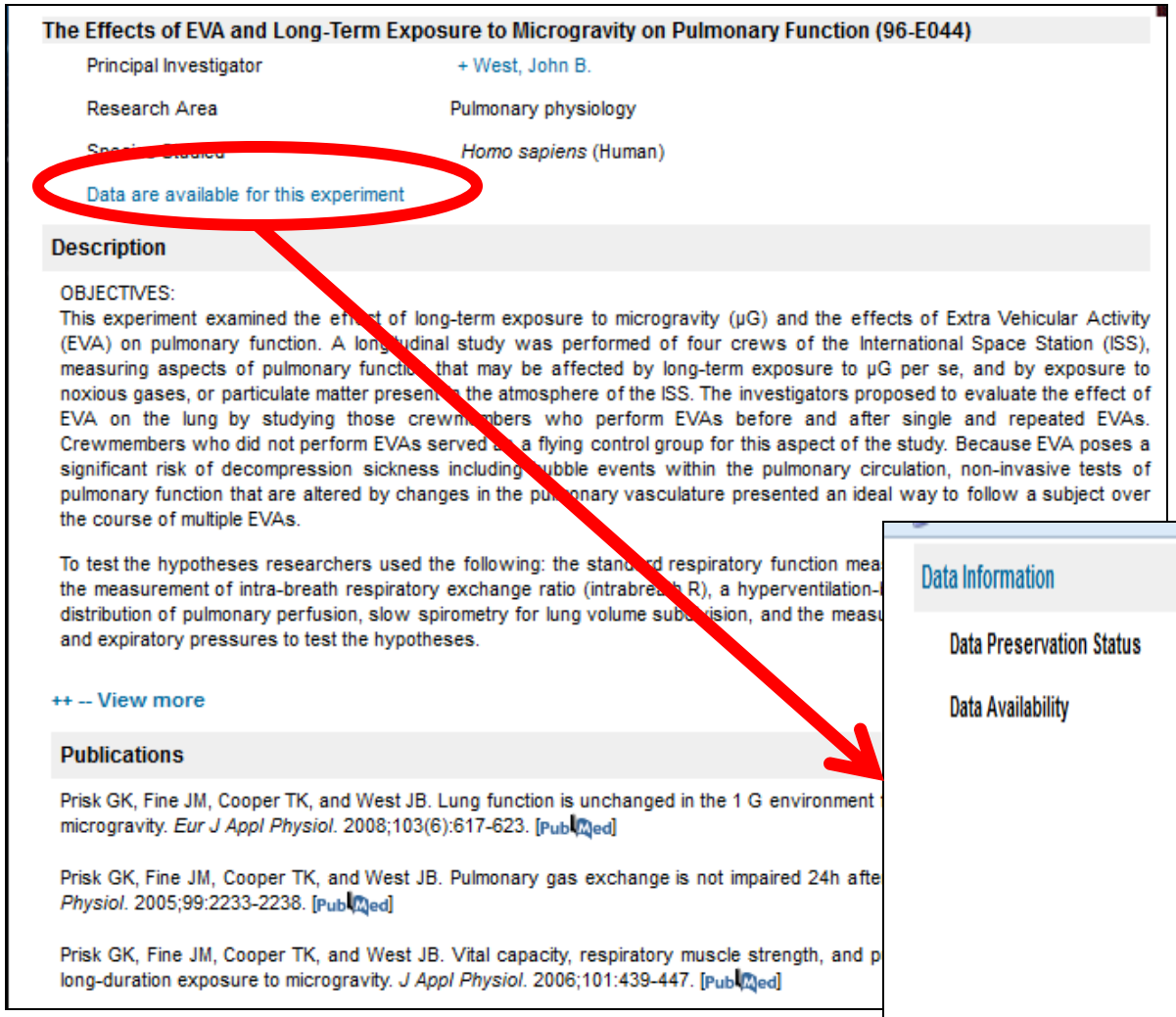
Searching for Specific LSDA Data





Search by keyword or other parameters through the 'Dataset' portal

Experiment-Specific Information



The Effects of EVA and Long-Term Exposure to Microgravity on Pulmonary Function (96-E044)

Principal Investigator + West, John B.

Research Area Pulmonary physiology

Species Studied *Homo sapiens* (Human)

Data are available for this experiment

Description

OBJECTIVES:
This experiment examined the effect of long-term exposure to microgravity (µG) and the effects of Extra Vehicular Activity (EVA) on pulmonary function. A longitudinal study was performed of four crews of the International Space Station (ISS), measuring aspects of pulmonary function that may be affected by long-term exposure to µG per se, and by exposure to noxious gases, or particulate matter present in the atmosphere of the ISS. The investigators proposed to evaluate the effect of EVA on the lung by studying those crewmembers who perform EVAs before and after single and repeated EVAs. Crewmembers who did not perform EVAs served as a flying control group for this aspect of the study. Because EVA poses a significant risk of decompression sickness including bubble events within the pulmonary circulation, non-invasive tests of pulmonary function that are altered by changes in the pulmonary vasculature presented an ideal way to follow a subject over the course of multiple EVAs.

To test the hypotheses researchers used the following: the standard respiratory function mea
the measurement of intra-breath respiratory exchange ratio (intrabreath R), a hyperventilation-
distribution of pulmonary perfusion, slow spirometry for lung volume subdivision, and the measu
and expiratory pressures to test the hypotheses.

++ -- View more

Publications

Prisk GK, Fine JM, Cooper TK, and West JB. Lung function is unchanged in the 1 G environment
microgravity. *Eur J Appl Physiol*. 2008;103(6):617-623. [PubMed]

Prisk GK, Fine JM, Cooper TK, and West JB. Pulmonary gas exchange is not impaired 24h afte
Physiol. 2005;99:2233-2238. [PubMed]

Prisk GK, Fine JM, Cooper TK, and West JB. Vital capacity, respiratory muscle strength, and p
long-duration exposure to microgravity. *J Appl Physiol*. 2006;101:439-447. [PubMed]

Data Information

Data Preservation Status	Preservation complete
Data Availability	This experiment has both unrestricted and restricted data (potentially attributable to human subjects).

+ View unrestricted data.

Please visit https://rlsda.jsc.nasa.gov to view the restricted data catalog.
This site is restricted to the JSC Internal Network (JIN) only.

+ Data request for restricted records

Information on Public Website lsda.jsc.nasa.gov

Medical Operations

The Space Medicine Division mission is to optimize the health, fitness, and well being of flight crews.

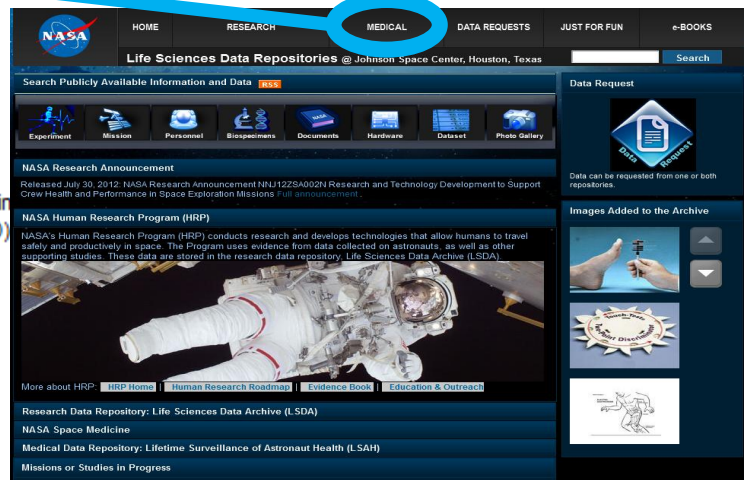
Astronaut medical data are collected per requirements detailed in the + Medical Requirements Integration Documents (MRID's).
Data collected during these medical tests are generally housed in the Lifetime Surveillance of Astronaut Health (LSAH) repository. These test protocols are divided into areas as shown below. Each MRID will give an indication of the type of testing performed as well as the frequency of such tests.

FIND IT @ LSDA Search

Click on an category image for relevant MRID information:

- Behavioral Health and Performance
- Bone, Muscle, Exercise
- Cardiovascular
- Environmental Health
- Extravehicular Activity (EVA)
- Immunology
- Neurology
- Nutrition
- Radiation
- Therapeutics and Clinical Care
- View All Medical Requirements

Note: The Medical Requirements Integration Documents (MRIDs) reflect the Medical Requirements documented in Requirements Document (AMERD), JSC 24834, the ISS Medical Operations Requirements Document (ISS MORD) Medical Operations Requirements Document (MORD) JSC 13956.



LSAH Publicly Available Information

Newsletters

- Published semi-annually to keep participants and stakeholders informed on the program's findings

National Aeronautics and Space Administration

THE LIFETIME SURVEILLANCE OF ASTRONAUT HEALTH

Newsletter

Spring 2012 Volume 10, Issue 1

Editor's Note: This spring's newsletter focuses on NASA's rapidly evolving interest in visual acuity changes associated with microgravity environments. There are currently a variety of theories and studies focusing on concerns recently brought to light, which we outline for you here. Lifetime Surveillance of Astronaut Health (LSAH) staff have spent countless hours on these investigations as part of our occupational surveillance program, and will continue to work towards better understanding and mitigating space flight health risks.

What's New in Space Medicine – Can you say "VIIP"?

By: William Tarver, MD

NASA has documented that several long duration astronauts have experienced in-flight and

the closest terrestrial clinical model for us to compare against, the NASA documented clinical entity remains

National Aeronautics and Space Administration

THE LIFETIME SURVEILLANCE OF ASTRONAUT HEALTH

Newsletter

Fall 2012 Volume 10, Issue 2

Editor's Note: This edition of the newsletter focuses on various programs and services provided by and in conjunction with the Lifetime Surveillance of Astronaut Health (LSAH). We feel it is important to keep you up-to-date with current program offerings, data uses, and upcoming organizational changes. Additionally, please see the last page for a slightly truncated list of publications that have resulted from astronaut data provided by LSAH.

Individual Exposure Profiles: Documenting and Evaluating the Risks to Astronaut Health

By: Jessica Garcia, MPH

This spring, the Lifetime Surveillance of Astronaut Health (LSAH) began a project to compile and verify astronauts' occupational exposures to hazards such as intense noise, injuries, and radiation. These Individual Exposure Profiles (IEPs) will document exposures over each astronaut's lifetime, with specific emphasis on those hazards unique to working at NASA. A more individualized health care protocol can then be created for each astronaut based on their specific risks. The project was conceived in an attempt to pull together hazard exposure and related outcome information from a variety of sources into one concise document for each astronaut. Information is gathered from sources such as the electronic medical record (EMR), the Shuttle Data Archive, the LSAH data base, the Life Sciences Data Archive (LSDA), mission and training documents, and biographical data. These data are put into a summary form that guides a one-time in-person interview, which is conducted by an epidemiologist at the time of the annual exam. This conference gives each astronaut a chance to verify the facts and add missing details.

LSAH is also interested in pre- and post-NASA exposures such as military service, previous work or childhood exposures, and current hobbies. Some astronauts may wonder why there are questions about non-NASA-related experiences, but these exposures are what could be considered a baseline. Without a comprehensive understanding of the whole risk profile of an astronaut, we can't properly assess the risk of space flight to current and future crewmembers. Additionally, these IEPs may help guide future attempts to secure legislation for federal funding of retired astronauts' healthcare, which requires a thorough understanding of the lifetime risks to astronaut health.

Currently, the focus is on completing IEPs for retired astronauts returning to JSC for their annual physicals, especially those who do not reside in the Houston metro area. Contact is most often made through email a week or two prior to the exam, and the interview generally occurs immediately following the physical in the Flight Medicine Clinic offices. While participation is not mandatory, LSAH hopes every astronaut will be enthusiastic to take part and help us better tailor our exams and, in the long run, ensure the health of the entire astronaut corps.

For past newsletters, please visit the LSAH website

Medical Requirements

- Documents outline medical tests performed on ISS crew
- Click blue text to see testing details to help determine the data you need

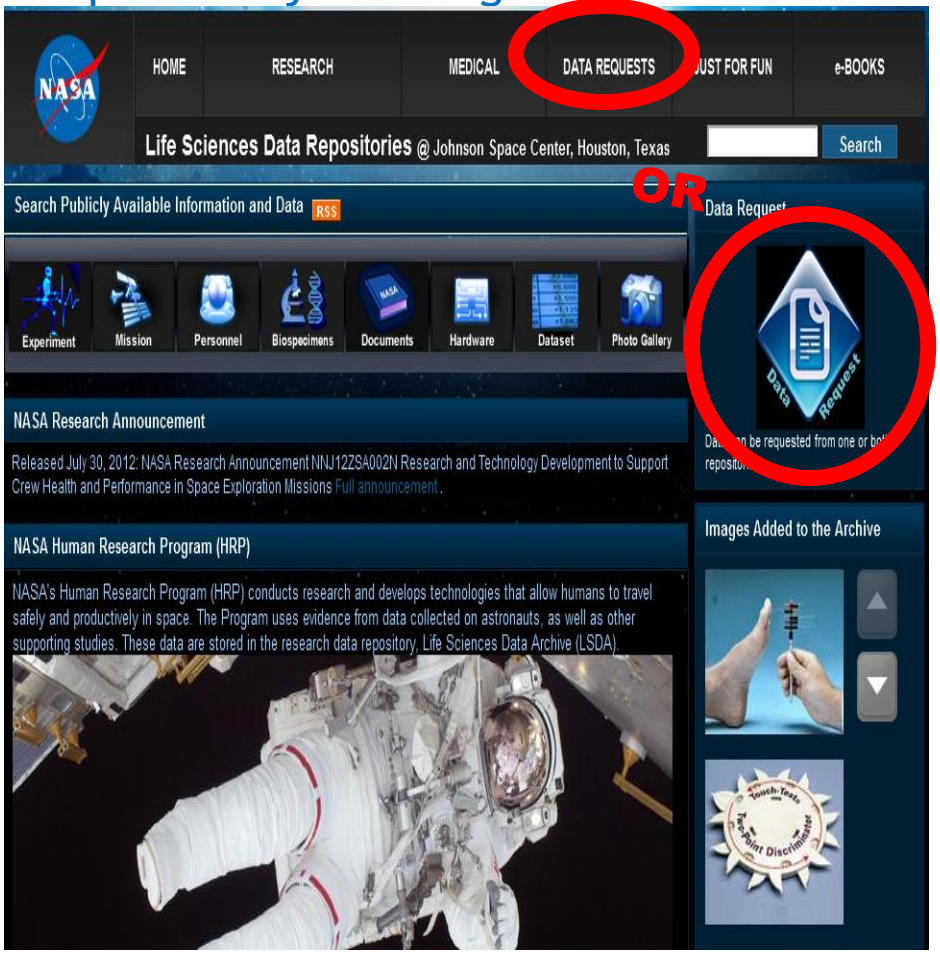
All Medical Requirements

Discipline	MRID#	MEDB#	Medical Requirement Title
Behavioral Health and Performance		MEDB 7.7	+ Behavioral Observation of Training
Behavioral Health and Performance		MEDB 7.4	+ Mood Assessment
Behavioral Health and Performance		MEDB 7.1	+ Preflight Behavioral Health Status Check
Behavioral Health and Performance	MR027L	MEDB 7.5	+ Post-flight Psychiatric/Psychological Evaluation
Behavioral Health and Performance	MR027L	MEDB 7.2	+ Preflight Evaluations
Behavioral Health and Performance	MR031L		+ Private Psychological Conferences (PPCs)
Behavioral Health and Performance	MR032L		+ ISS Private Family Conferences (PFCs)
Behavioral Health and Performance	MR032S		+ Private Family Conferences (PFCs) for Shuttle Crews
Behavioral Health and Performance	MR085L	MEDB 7.6	+ Neurocognitive Assessment
Bone, Muscle, Exercise		MEDB 5.4	+ Calf Volume Measurement
Bone, Muscle, Exercise		MEDB 5.1	+ Functional Fitness Assessment
Bone, Muscle, Exercise	MR006L		+ Exercise Treadmill Test
Bone, Muscle, Exercise	MR019L		+ Heart Rate Monitoring
Bone, Muscle, Exercise	MR026L		+ Postflight Rehabilitation

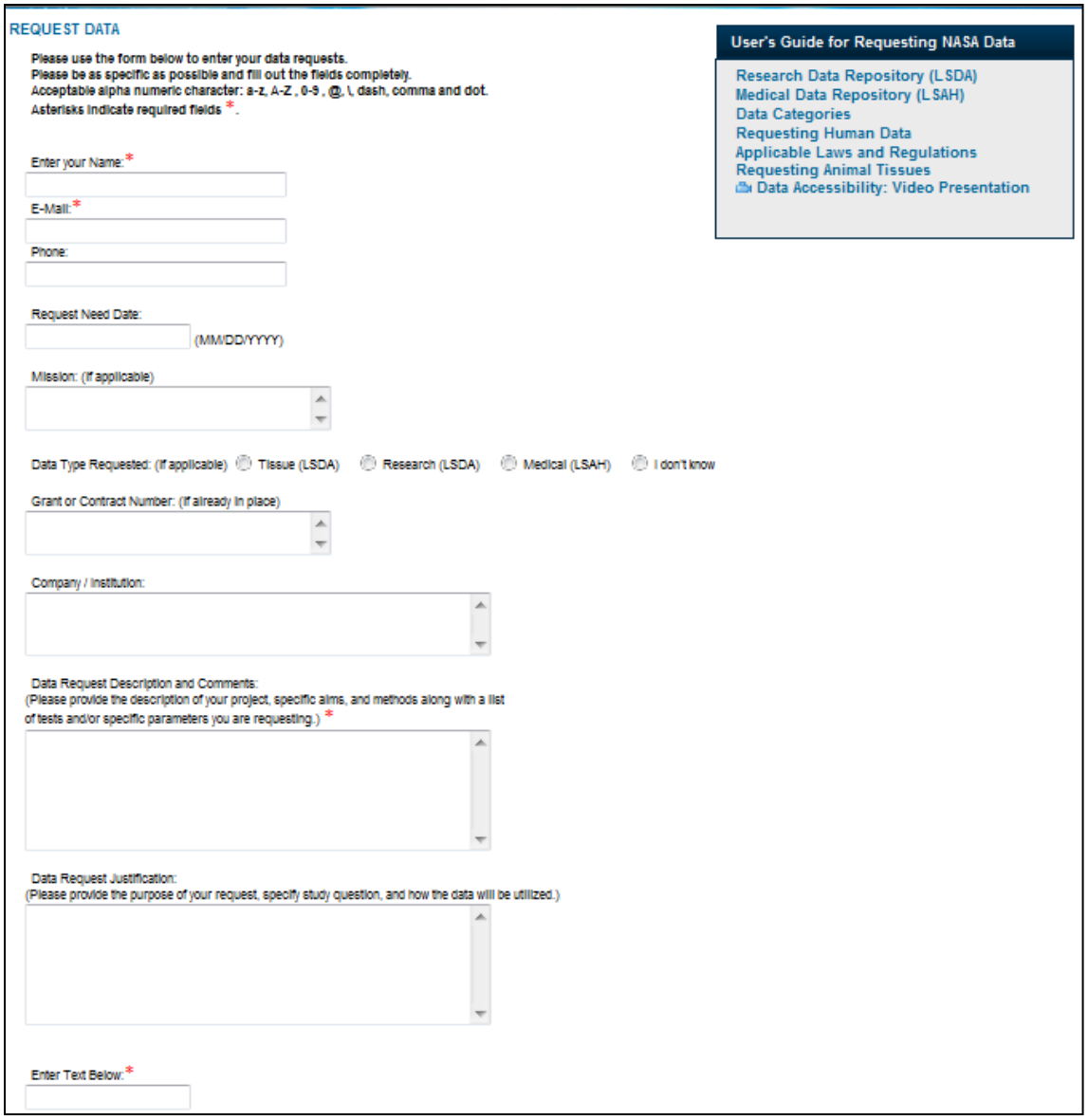
Requesting Data Not Available on Website

- Individual astronaut data are not downloadable
  - Potentially attributable to a subject
  - Protected by the Privacy Act
- HOWEVER, individual data can be requested for research, medical and operational purposes

http://lsda.jsc.nasa.gov



Data Request Form



REQUEST DATA

Please use the form below to enter your data requests.
Please be as specific as possible and fill out the fields completely.
Acceptable alpha numeric character: a-z, A-Z , 0-9 , @, \, dash, comma and dot.
Asterisks indicate required fields *.

User's Guide for Requesting NASA Data

- Research Data Repository (LSDA)
- Medical Data Repository (LSAH)
- Data Categories
- Requesting Human Data
- Applicable Laws and Regulations
- Requesting Animal Tissues
- Data Accessibility: Video Presentation

Enter your Name:*

E-Mail:*

Phone:

Request Need Date: (MM/DD/YYYY)

Mission: (if applicable)

Data Type Requested: (if applicable) Tissue (LSDA) Research (LSDA) Medical (LSAH) I don't know

Grant or Contract Number: (if already in place)

Company / Institution:

Data Request Description and Comments:
(Please provide the description of your project, specific aims, and methods along with a list of tests and/or specific parameters you are requesting.) *

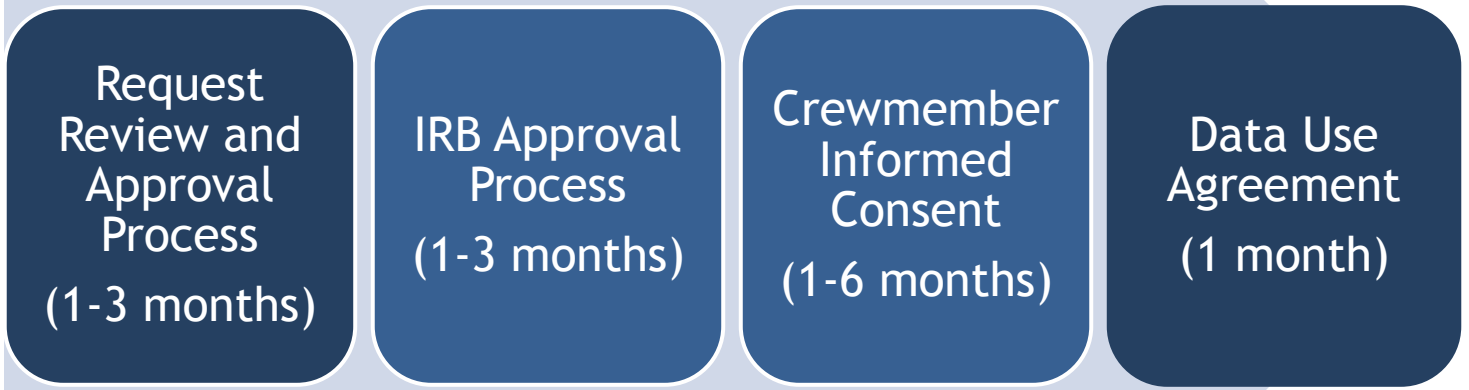
Data Request Justification:
(Please provide the purpose of your request, specify study question, and how the data will be utilized.)

Enter Text Below:*

Your request should include:

- Contact Information
- Need-by Date
- Grant, NRA#, or current project data will support
- Institution
- "Data Request Description" – i.e., specific data you are requesting
- "Data Request Justification" – i.e., purpose for which data is required

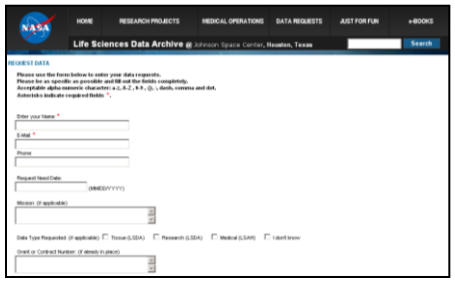
Data Request Timeline



Factors Contributing to Longer Timeline:

- Need for individual, attributable data (such as to match medical with your research data ID codes)
  - Informed consent process can be lengthy, especially for large 'n' and obtaining consents from retired astronauts
- Need for large or complex data sets, particularly those with missing data
- Need to share the data with an investigator team far apart geographically (data transfer/security issues)

Data Request Fulfillment



Data Request Clearinghouse

Automated email to requester

Obtain more info

Data Availability Check

LSAH Data

LSDA Data

Confirm with Requester

Request Approval Process:

- ✓ Request purpose?
- ✓ Merit established?
- ✓ Attributable data?
- ✓ IRB review required?
- ✓ Consent necessary?

Request not approved

Notify requester; modify request

Request approved

Requester notified of anticipated schedule; signs data use agreement if required

Assimilate Data from Various Sources

Mission Medical Records
LSDA Archive
Training Records
Clinic/LSAH Records
Vehicle Environmental Data
Biospecimen Data
Research Study/Laboratory Data
Questionnaires/Surveys

Retrieve missing data

Perform Data Quality Assurance

Consent Forms Complete (if req'd)

Data sent to Requester

Progress on Challenges from 2011, 2012

- **INFORMED CONSENT**
  - LSAH and LSDA Repositories have begun consent process with ISS crewmembers for use of their medical and research data for future approved studies
  - Resources for interim consenting for retrospective studies need to be identified until all crewmembers' repository consents are completed

- **DE-IDENTIFICATION OF DATA**
  - Privacy challenges, even with some grouped data, due to small 'n', public information available about subjects
  - Informed consent will help with this issue
  - Meanwhile, continuing to work on manual techniques to remove identifiers from images, metadata

Progress on Challenges from 2011, 2012 (cont.)

- **GAPS IN ARCHIVED DATA**
  - New HRP contract requirements will help assure future archiving of research data
  - Improved Data Submission Agreements (DSAs) assure all parties have reasonable expectations
  - LSAH has had some success compiling medication data and information from other sources such as operations team notes, environmental data
  - New tools and processes have been developed to better archive medical data as it is collected (e.g., inflight vision data, private medical conferences, Electronic Medical Record-LSAH interface improvements)

- **REQUESTER EXPECTATIONS**
  - We are trying to provide transparency and education about processes and lead times
  - We are taking action on comments received in surveys and other feedback
  - LSAH received HRP funds this year to better support research community

New Challenges

- **INTEGRATION WITH THE HRP, IRB**
  - Working on processes to integrate better with HRP during research planning – identify early any needs for retrospective data
  - Identifying responsibilities and resources for informed consenting for studies using retrospective data
  - Collaborating with IRB to gain efficiencies, ensure availability and board approval of data requested

- **INCORPORATION OF OTHER DATABASES**
  - New HRP "Human Performance Data Project"
  - Integration of existing human data all in one place, incorporation into the existing LSDA-LSAH model

Conclusion

We are committed to fulfilling your data request needs

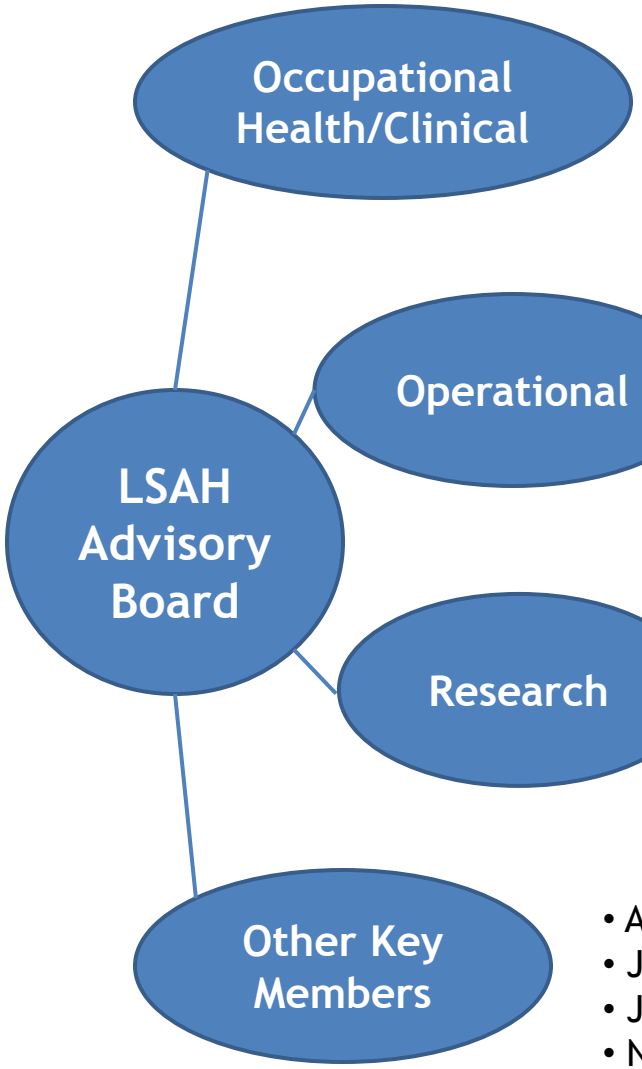
Please come see these related posters

- "Improving Acquisition, Preservation, & Distribution of Human Research Data"
- *"The LSDA Animal and Plant Holdings at Ames Research Center"*
- "Human Performance Data Base Project"
- *"Evaluation of Crew Exposure to Mild Hypobaric Hypoxia"*

Backup Slides

LSAH Advisory Board

Chair: Chief, Space & Clinical Operations Division or designee



- Occupational Health Branch Chief
- Medical Operations Group Lead
- JSC Clinic Medical Director
- Crew Health & Safety Physician Liaison
- LSAH Program Manager

- Information Systems Architecture Branch Chief
- ISSMP Representative*

- HRP Chief Scientist
- Biomedical Research & Environmental Systems Division Chief
- Human Systems Engineering & Development Division Chief
- LSDA Manager
- BDRA Project Manager*
- International Science Office Chief

- Astronaut Office Physician Representative
- JSC Legal Office Representative
- JSC Institutional Review Board Chair
- NSBRI Representative (physician)

*Dual assignment

Board Purpose

This board reviews:

- All requests for attributable data (except clinical care)
- Other requests forwarded to the board by EBWG
- Requests where NASA policy is not yet determined

Meets 4th Tuesday of each month

Evidence Base Working Group Membership

Group Purpose

EBWG is the clearinghouse for all incoming data requests

Releases public or un-attributable data

Facilitates data requests through approval processes to release

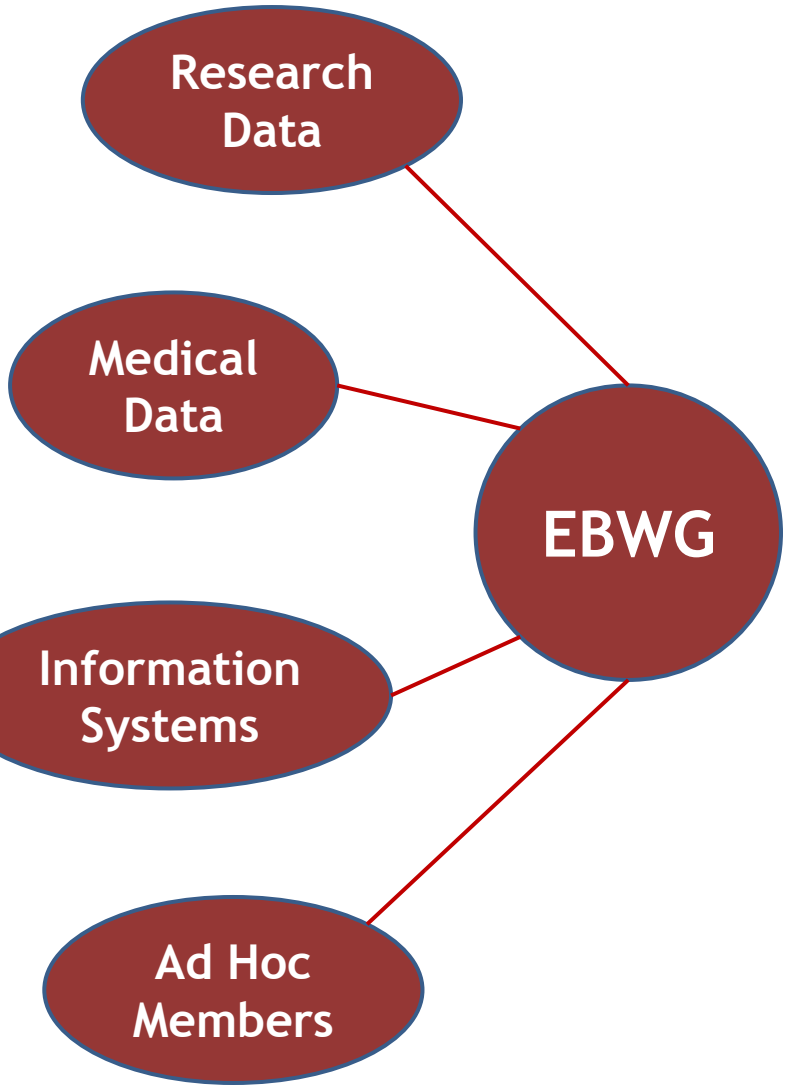
Meets every other Monday

- LSDA NASA Manager
- LSDA Archivists

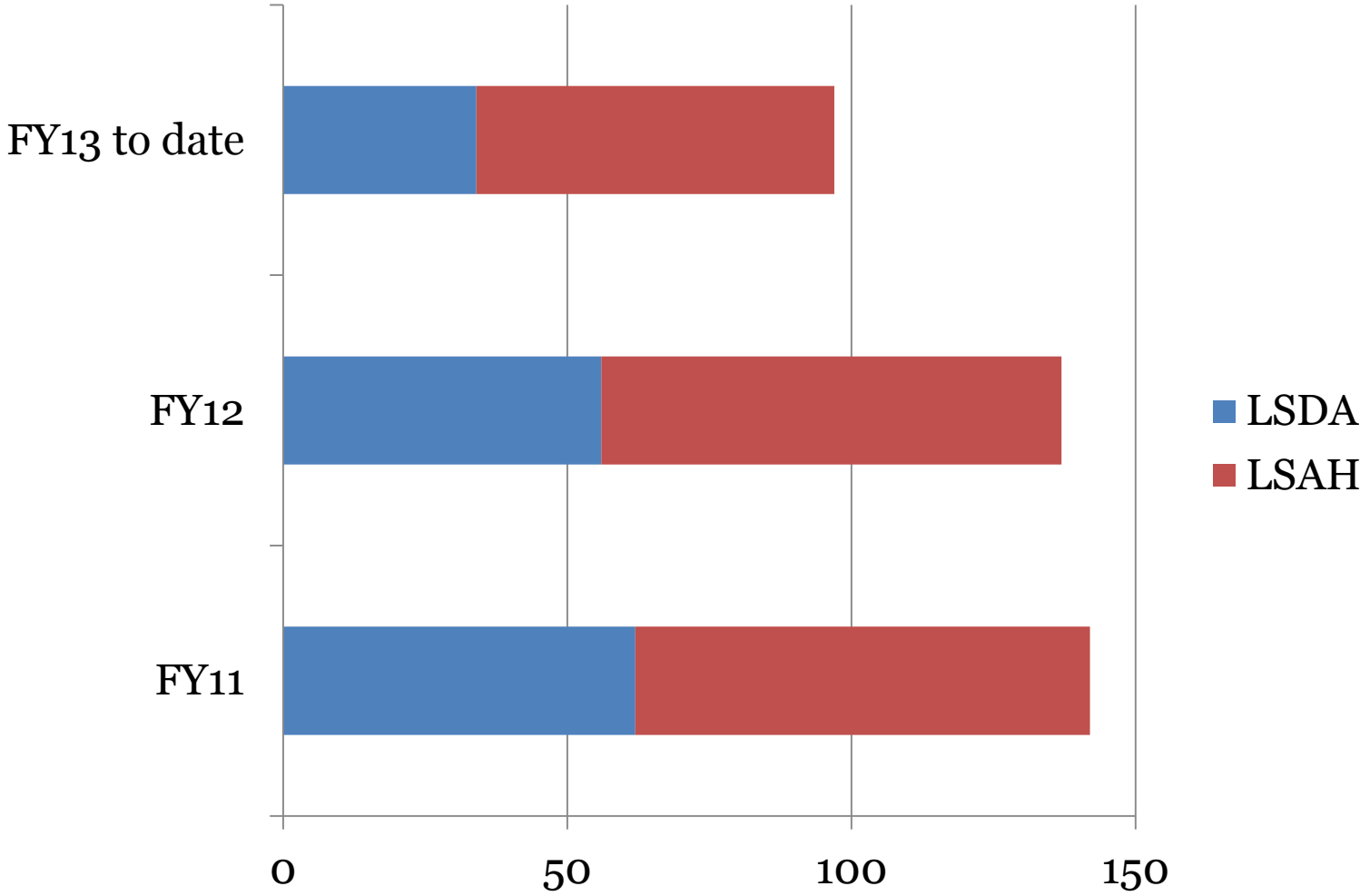
- LSAH NASA Manager
- Epidemiology Manager
- LSAH Epidemiologists
- BDRA Epidemiologist

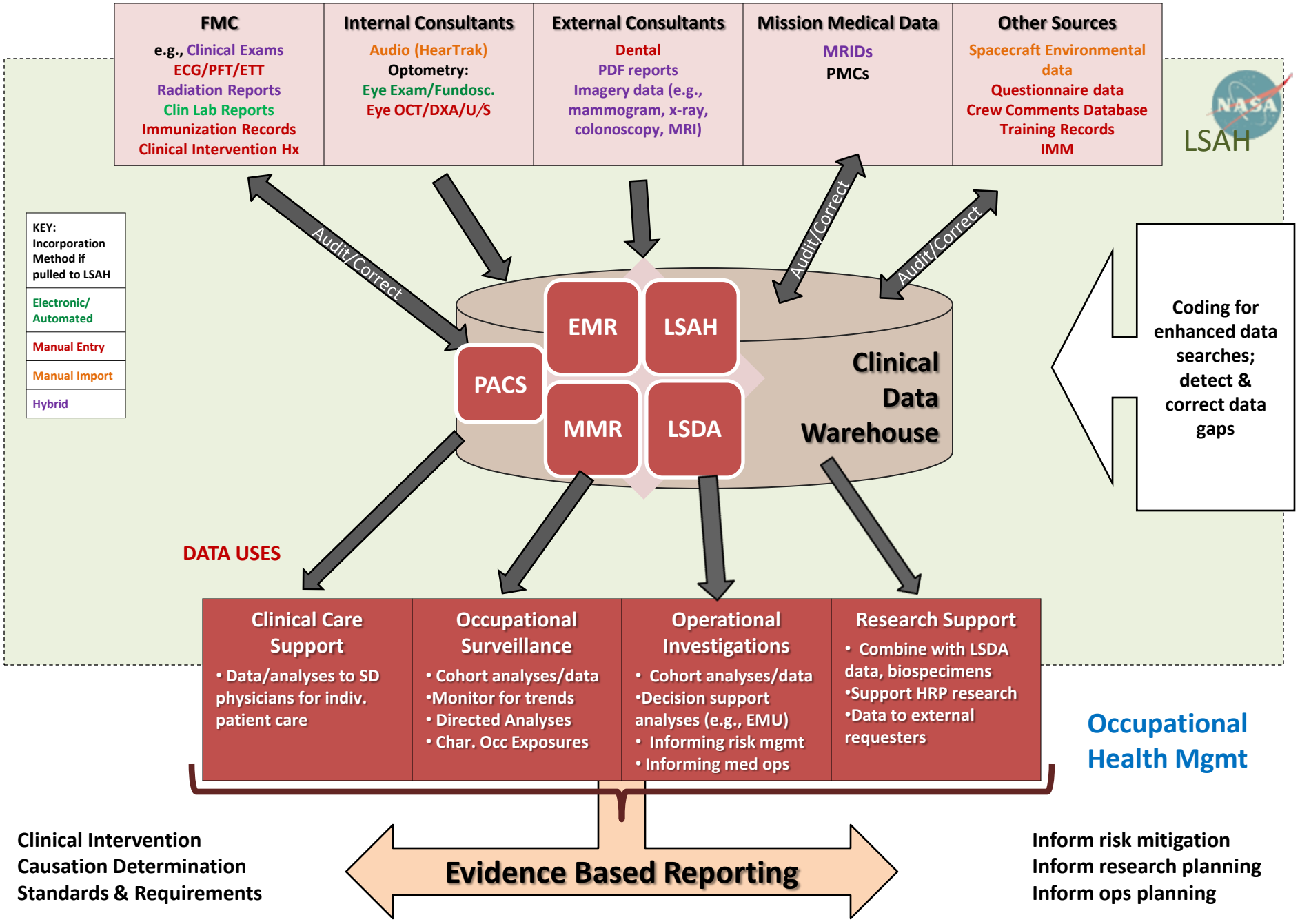
- Information Systems Architecture Branch Chief
- *Space Medicine, LSDA IT staff (consultants)*

FUTURE?
- Human Performance Data Base staff
- Other archive managers



Data Request Successes




FMC
e.g., Clinical Exams
ECG/PFT/ETT
Radiation Reports
Clin Lab Reports
Immunization Records
Clinical Intervention Hx
Internal Consultants
Audio (HearTrak)
Optometry:
Eye Exam/Fundosc.
Eye OCT/DXA/U/S
External Consultants
Dental
PDF reports
Imagery data (e.g., mammogram, x-ray, colonoscopy, MRI)
Mission Medical Data
MRIDs
PMCs
Other Sources
Spacecraft Environmental data
Questionnaire data
Crew Comments Database
Training Records
IMM
LSAH
KEY:
Incorporation Method if pulled to LSAH
Electronic/ Automated
Manual Entry
Manual Import
Hybrid
Audit/Correct
Audit/Correct
Audit/Correct
EMR
LSAH
PACS
MMR
LSDA
Clinical Data Warehouse
Coding for enhanced data searches; detect & correct data gaps
DATA USES
Clinical Care Support
• Data/analyses to SD physicians for indiv. patient care
Occupational Surveillance
• Cohort analyses/data
•Monitor for trends
• Directed Analyses
• Char. Occ Exposures
Operational Investigations
• Cohort analyses/data
•Decision support analyses (e.g., EMU)
• Informing risk mgmt
• Informing med ops
Research Support
• Combine with LSDA data, biospecimens
•Support HRP research
•Data to external requesters
Occupational Health Mgmt
Clinical Intervention
Causation Determination
Standards & Requirements
Evidence Based Reporting
Inform risk mitigation
Inform research planning
Inform ops planning